healthwatch York

Continuing Healthcare

March 2017

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What is Continuing Healthcare?

NHS Continuing Healthcare is the name given to a package of care that is arranged and funded solely by the NHS for people who are not in hospital and have been assessed as having a ‘primary health need’.

It can be provided:

- in your own home – the NHS will pay for healthcare, such as services from a community nurse or specialist therapist, and personal care, such as help with bathing, dressing and laundry
- in a care home – as well as healthcare and personal care, the NHS will pay for your care home fees, including board and accommodation

NHS Continuing Healthcare is free, unlike social and community care services provided by local authorities. For social care, you may be charged depending on your income and savings. [i]

Eligibility

To be eligible for NHS Continuing Healthcare you must be over 18 and have substantial and ongoing care needs. You must have been assessed as having a "primary health need". [ii]

When assessing your eligibility for NHS Continuing Healthcare, staff must follow certain processes. You must be assessed by a team of healthcare professionals as having a ‘primary health need’ which means that you need care primarily because of your health needs.

Whether or not someone has a ‘primary health need’ is assessed by looking at all of their care needs and relating them to four key indicators:

- **nature** – the type and particular characteristics of their needs and the overall effect these needs have on the person, including the type of interventions required to manage those needs

- **complexity** – the complexity of the person's needs and the level of professional skill required to monitor the symptoms, treat the condition and/or manage the care
- **intensity** – how intense and severe the person's needs are and the support needed to meet them, including the need for sustained and/or ongoing care
- **unpredictability** – how hard it is to predict changes in a person's needs that might create challenges for the professionals who manage them, including the risks to the person's health if adequate and timely care is not provided

Eligibility is always based on these needs, it does not depend on:

- a specific illness, diagnosis or condition [iii]
- who provides the care, or
- where the care is provided

If you are assessed as eligible for Continuing Healthcare, your care will be funded by the NHS. Eligibility is subject to regular reviews and if your care needs change, the funding arrangements may also change. [iv]

Having a disability or having been diagnosed with a long-term illness or condition, this doesn't necessarily mean that you are eligible for NHS continuing healthcare.[v]

When should you be considered for NHS continuing healthcare?

If you have ongoing health needs, there are times when staff should consider whether you may need a full assessment for NHS continuing healthcare.

The times include:

- when you are ready to be discharged from hospital and your long-term needs are clear
- when a period of intermediate care or rehabilitation following a hospital stay has finished and it is agreed that your condition is unlikely to improve

- whenever your health or social care needs are being reviewed as part of a community care assessment
- if your physical or mental health deteriorates significantly and your current level of care seems inadequate
- when your nursing needs are being reviewed. Nursing needs should be reviewed annually if you live in a nursing home

There is also a Fast Track process for Continuing Healthcare:

- if you have a rapidly deteriorating condition and may be approaching the end of your life

In the circumstances listed above, discharge staff, staff co-ordinating your intermediate care, your GP or a member of the social work team should tell you about Continuing Healthcare and assess your eligibility for a full assessment. If they don't you can ask for an assessment.[vi]

How people are assessed – the National Framework

The purpose of the National Framework is to provide fair and consistent access to NHS funding across England, regardless of location, so that people with similar needs are equally likely to get all their health and nursing care provided free of charge, no matter where they live.[vii]

What the assessment process should be like:

The whole decision-making process should be 'person-centred'. So if you are being assessed you, and your views about your needs and the care and support required, should be at the centre of the process. It also means making sure that you play a full role in the assessment and decision-making process and get support to do this if you need it. For example you can ask a friend or relative to help you explain your views.[viii]

The process has a number of steps.

1. Health and social care staff use the four key indicators (listed earlier on pages 3-4) to assess whether a full assessment is required.

2. If a full assessment of eligibility is required, the Clinical Commissioning Group (CCG) will arrange for a multi-disciplinary team (MDT) to carry it out. If permission is given, the assessment will involve contributions from all health and social care professionals involved in your care. The MDT can request a more detailed, specialist assessment carried out by these professionals.

   To help them make decisions on eligibility, staff use a *Decision Support Tool,* which looks at 11 different types of needs including mobility, nutrition and behaviour as well as the key indicators of whether you may have a primary health need.

   If your health is failing and you are close to end of life you may need an 'urgent package of care due to a rapidly deteriorating condition which may be entering a terminal phase'.[ix] In this case a *Fast Track Tool* is used, which is completed by an appropriate clinician, and sent directly to the CCG.

   After the assessment, if you are eligible, a recommendation for NHS Continuing Healthcare is made to the CCG. The recommendation will be accepted unless there are exceptional circumstances.[x]

3. Following every assessment or review a written decision should be sent to you.

The process for putting care in place

The CCG should discuss the options for meeting and managing your care and support needs with you, including which organisations will be responsible.

You should have your wishes and expectations of how and where care is delivered taken into account and documented.

Reviews

Reviews should take place after 3 months, and then at least every year.

Neither the NHS nor the local council should withdraw from an existing care or funding arrangement without a joint review and reassessment of the person's needs. They must consult one another, and the person

receiving care about any proposed changes and make sure that alternative funding or services are in place. [xi]

What happens if you are denied funding?

- If some health needs have been identified alongside social care needs, the NHS may fund part of a package of support – this is known as a 'joint package' of care which can be through NHS-funded nursing care, or other services
- Where the local council is also part funding a care package then, depending on income and savings, you may have to pay a contribution towards the costs of their part of the care. There is no charge for the NHS part of a joint package of care[xii] and it is not means tested
- You will continue to receive free care from universal services, for example their GP, community teams and hospitals

What can you do if you are unhappy?

If you disagree with a decision not to proceed to full assessment of eligibility for NHS continuing healthcare following completion of a checklist you can ask the CCG to reconsider the decision.

If you disagree with the eligibility decision made by the CCG (after a full assessment and the Decision Support Tool has been completed) or if you have concerns about the process used to reach the decision, you can write to the CCG to request a local resolution review of your case. If the matter cannot be resolved locally you may appeal to NHS England requesting an Independent Review Panel.

Everyone has a right to complain about any aspect of the service they receive from the NHS, the local authority, or any provider of care. The details of the complaints procedure are available from the relevant organisation, including details of advocacy services.[xiii]

How many people receive NHS Continuing Healthcare?

From April 1st 2013 to December 31st 2015, the number of people newly eligible for Continuing Healthcare in the Vale of York area was 21.8 per 50,000 population. This means that, during this period, about 150 people (out of a total 350,000 population) across the Vale of York were newly

eligible for Continuing Healthcare. The proportion of the population newly eligible in the Vale of York is lower than the regional and national averages during this period.[xiv]

Vale of York	21.8 per 50,000 population
Yorkshire and Humber regional average	30.1 per 50,000 population
National average	27 per 50,000 population

The total number of people receiving Continuing Healthcare in the Vale of York from April 1st 2013 to December 31st 2015 was 45.7 per 50,000 population. The national average is 67.5 per 50,000.

These figures relate to Continuing Healthcare only. Within this report, we also talk about joint funded packages, fast track, and funded nursing care.

Why is Healthwatch York looking at Continuing Healthcare?

From 2013 to 2015 Healthwatch York received a small number of serious concerns about the Continuing Healthcare process. In January 2016 the topic was chosen in our work plan survey when 32% of respondents voted Continuing Healthcare as one of the top three priorities for Healthwatch York to look at.

Comments made in survey responses included:

> *I have a long term illness and was in the financial position to take out health insurance easily in my working life. I have benefitted from that since… others are not so fortunate…*

> *The criteria for Continuing Healthcare are often misunderstood and wrongly applied, resulting in hardship from wrong assessments.*

> *Totally unfair that my father was in a residential and nursing home and it cost £150,000 of our inheritance to fund it when he was in with people who had not paid taxes all their lives and did not have their own home to sell. We are in the process of appealing as he should have been in nursing care.*

> *The whole picture is complex and considerably difficult to navigate.*

Continuing Healthcare has been the subject of ongoing local concern, highlighted regularly through NHS Vale of York CCG's Quality and Patient Experience Reports and Risk Registers.[xv] Most recently, at the CCG Governing Body meeting of 5 January 2017, the following concern was noted in the risk register:

> *"Continuing Healthcare (CHC): Costs of packages remain high across a number of patient cohorts which is impacting on the overall cost of both Funded Nursing Care (FNC) and CHC activity. A range of options to address the specific pressures relating to this issue are being explored with partners as part of the wider system conversations."*

Within the risk register, there is acknowledgement of "resourcing issues in relation to regular and timely assessments in accordance with best practice guidance." Actions taken in mitigation are that "PCU [The Partnership Commissioning Unit, which acts for the 4 CCGs across North Yorkshire and York] have now got a plan in place and additional resource to tackle the historic backlog of cases and have a deadline of 31st October 2016 to achieve clearance of the backlog." The latest update confirms that "PCU is now working closely with local authority and health partners to address the concerns highlighted in recent reviews and these should be implemented during 2017."

Within the Quality and Patient Experience report at the same meeting, the CCG provided an update on retrospective appeals concerning Continuing Healthcare. This update included one instance of a family who had appealed the decision to an independent review panel, facilitated by NHS England.

Description	Status	Total
Local resolutions	Pending	28
	Complete	7
Independent Review Panels	Pending	0
	Complete	1

Continuing Healthcare has also been the subject of national media attention, with the Mirror online in particular running regular stories about entitlement to "secret" funding.[xvi] A recent article, on Wednesday 26thOctober 2016 "Putting the fair back into NHS care" highlighted a drop in the total number of people receiving Continuing Healthcare – from 62,939 in 2014/15 to 59,377 in 2015/16. The article also highlighted differences in eligibility across different localities, with 237 per 50,000 people receiving CHC in Salford, compared with only 57 per 50,000 in London.

More recently, NHS England have launched a new national NHS Continuing Healthcare Strategic Improvement programme[xvii]. They confirm that a collaborative engagement method will be at the centre of the programme. Through this, they will work with CCGs to identify best practice and explore new approaches to improve NHS Continuing

Healthcare. Introductory webinars ran on 10th and 12th January 2017. NHS Vale of York Clinical Commissioning Group were involved in these.

What we did to find out more

We undertook desk research, looking at local media stories and comments about experiences of continuing healthcare.

We ran a survey which, although we did not receive many responses, gave us an understanding of how it feels to go through a Continuing Healthcare assessment. These responses included some from across the wider North Yorkshire area, although we have limited our recommendations and actions to our own geographical area.

We invited people to a focus group to discuss Continuing Healthcare. At the focus group we spoke with two carers about their experiences of the Continuing Healthcare process. One of these experiences is described in detail as a case study later in this report (Case study 1). The second experience is subject to a review regarding retrospective funding and in order not to compromise the review we have only provided a brief summary of the concerns raised (Case study 2).

We also reviewed our issues log, which contained further personal experiences around Continuing Healthcare.

What we found out

Local media stories and comments

The Press, 21 April 2014 – "Families wrongly selling off their family home to pay for care home fees"[xviii]

"*Too many families in North Yorkshire and York are wrongly selling off their family home to pay for care home fees, according to the authors of a new guide launched by Gloria Hunniford.*

The average cost of a UK nursing home is £738 per week – that's almost £40,000 a year. But many families struggle needlessly to come up with the cash in a situation where they may be eligible for full funding from the NHS, although few people know about it specialist care funding solicitors Farley Dwek, which produced the new guide, have warned.

This is known as NHS Continuing Healthcare and is not means-tested. It is based on assessments of healthcare needs, such as mobility and severity of conditions, the firm said.

The latest figures, from 2013, show just 537 people in the old North Yorkshire and York PCT (now the four separate CCGs) were receiving continuing health care funding from the NHS.

There could be hundreds or thousands more who are missing out on financial support. Gloria Hunniford said: "The funding process can be complicated and not enough people understand it. Too many families feel as though there is a lack of help out there and are missing out on funding they are entitled to as a result."

To download the free guide visit www.farleydwek.com"

The Press, 20 August 2015 - "Man, 81, stranded in York Hospital for 6 weeks due to bed blocking crisis" [xix]

In August 2015 Debra Edwards raised concerns about the treatment of her father, Michael Fitzsimmons. She held power of attorney for her father. She stated "I feel he has been treated really badly. I believe it's to do with finances. I'm worried if something is not done, my dad will die." Michael, 81, had dementia and complex needs following a serious stroke 2 years earlier. In August, he had been in hospital for 6 weeks having become ill with pneumonia. The care home he was in previously stated they were not equipped to continue looking after him. The nearest home

offered to the family was in Hornsea. As Debra and her husband visited daily and helped him to eat she was concerned about the detrimental impact of him being placed so far away.

Michael passed away in hospital on January 22nd 2016.[xx]

The Press, 1 August 2015 - comment[xxi]

Ehullis3823, commenting on a story about the awarding of the mental health services contract:

Given my experience of the Vale of York CCG over another matter regarding NHS Continuing Healthcare for a member of my family they are clearly a "closed shop" when it comes to criticism. Something has to change. They, in my experience, are only concerned with budgets and power. It would be interesting to see whether they will give open discussion because in my experience they get all legal when they are challenged.

Healthwatch York Continuing Healthcare Survey results

We received 12 responses to our survey in 2016, 2 from people receiving continuing healthcare, 1 waiting for assessment, 5 relatives, and 4 health professionals. 8 were from York, 3 from Scarborough, and 1 from Ryedale.

Only 6 respondents had been through the initial application process. We asked whether people were familiar with Continuing Healthcare before applying for an assessment. The survey showed that half of respondents were. Half had heard about Continuing Healthcare from a social worker, and the rest heard from a nurse, other health professional, or voluntary sector agency. Half of the respondents were supported by a health or social care professional to apply. One respondent commented "was not supported – was told would not get continuing care, so not to bother". Only 2 were consulted before the application was made.

3 people commented on their experiences of the application process:

> "*I didn't realise that it was ongoing"*

"After we were told, in so many words, not to bother, we pursued legal action but it was so expensive we decided not to pursue it at that point"

"The continuing care was for my mother who was admitted into a residential and combined nursing home – we felt that she needed nursing and were told not, although within a couple of weeks they found in the home that she did indeed require nursing. We were not informed of the differences between continuing care and other care. We were told by the Carers Centre, who we approached by phone for a different reason, and their advisor asked if we had applied or been informed of continuing care. Despite having a social worker and a range of physio / doctors involved in my mother's care and admitting her into a home we were not told of any carers assessment or the continuing care application / options."

3 people responded to a question asking how long they had waited for the initial assessment checklist to be completed. 1 was completed within 1 week, 1 took 1-3 weeks, and 1 took 1-2 months.

5 people responded to a question asking whether they had been given a copy of the completed checklist. Only 1 of the 5 respondents had.

We asked "were you told that being referred for a full assessment doesn't necessarily mean they were eligible for Continuing Healthcare?" 3 people responded to this question, 2 felt the reasons for the decision were fully explained, 1 did not. 2 received feedback in person, 1 by letter.

Respondents told us that waiting times for the full assessment following completion of the initial checklist varied, from 1-3 weeks to over 6 months.

Three quarters of survey respondents felt the assessor asked the right questions, understood their condition and care needs, felt listened to during the assessment process, and felt their views and those of family members were taken into account. Half said they felt respected, and that the assessor focused on them and their needs.

Of the 2 respondents who were receiving Continuing Healthcare, 1 was receiving care in their own home, the other in hospital. We asked “were you given any choice about how and where your care would be provided?” 1 was unsure, the other said “yes – limited choice.” We also asked if they had been given the option of a personal health budget. 1 said no, 1 did not know.

1 person had received a review of their care needs, between 9 and 12 months ago. They were satisfied with the review process, and hope it continues.

Case studies (from Healthwatch York’s Continuing Healthcare focus group August 5th 2016)

Case study 1 - Naomi* (her story was told to us by her friend and carer)
*not her real name

“It was a good death for Naomi but the lead up was horrendous for friends and family. Naomi did not get the outcomes she wanted. She had cancer – a mango sized tumour by the time it was diagnosed. Naomi was a smoker. She’d given up a couple of times but on diagnosis she started again. She enjoyed smoking and it seemed pointless not to now.

Naomi had been a home care worker. She did not want a package at home because of this, but it was where she wanted to die. She was on chemo and radiotherapy, but it was palliative care. She was also on opiates. The tumour was pressing on her oesophagus, causing her to be sick. She was put on a syringe driver, which needed to be changed every 24 hours. But she had issues with the community nurses, they could only do this in twos, and there was no flexibility on the times.

Naomi always rose at 5am. It was mid-December, and she was still getting up early but she was tired. She ended up on the floor, with her foot wedged under the commode. On Boxing Day she was taken to St Leonard’s Hospice. She had 2-3 spells there. The nurses were lovely and the food was great. But there is nowhere at St Leonard’s Hospice where you can smoke. She had to be taken out to smoke, but it wasn’t easy to help her get about. She could not get any support from care assistants working at the hospice to go outside. The smoking area is a

long way from the hospice. You can understand it, but for Naomi she was unsteady and it was the middle of winter. It wasn't ideal.

Just to restate, her goal was to die at home, surrounded by friends, and smoking when she wanted to. We couldn't get her home easily, so we all mucked in, did the next best thing and set up a rota so she'd have her friends and family around, from December through til March, from 8am to 8pm at St Leonards.

Naomi had no money. She worked for a care agency. She was on statutory sick pay only. She didn't want to send off the Employment Support Allowance form. Someone from the council was helping her with filling in the forms. We wanted to get her home. Then someone asked, are you on Continuing Healthcare. She was being assessed, but not fast tracked. She was at end of life.

There was a real danger point between 3 and 5am. But no-one would put in overnight care at home. She had to have either 4 calls plus whatever Marie Curie could offer, or residential care. A social worker offered to arrange live in care for the same cost as residential, working with the family and friends who were caring for Naomi.

Eventually, Naomi did get Continuing Healthcare and got carers in to support her through an agency. One carer asked to smoke her cigarettes, one talked about not having any money. We didn't have any faith in the agency. Marie Curie could do 2-3 nights a week. But they could only say which 1 week before. We never saw a nurse during this time.

The ideal scenario for Naomi was to be at home, smoking when she wanted to, with some companionship. We were told, if we organised care as she wanted with each of us stepping in and using agencies we trusted, the Continuing Healthcare package would stop. It's so sad when we know we could have put this care in place if she knew she could have the money to cover it.

She knew she was at end of life in January. Before she died, she ended up back in the hospice. I believe this was purely because she was not

free to arrange the care she wanted. She died on 8th March. She had a very peaceful death, but it wasn't what she wanted.

The process is really rigid, there's no flexibility. This makes it harder for people to get what they need from it. There are frameworks, checklists and timescales.

Naomi got Disability Living Allowance quite quickly, based on having less than 6 months to live. When you are given a terminal diagnosis, you have to deal with grief and fear. The last thing you want to worry about is money. You want to do things with the limited time you have left. Naomi and her daughter asked about direct payments. They were told this would take too long.

There are market challenges in York – there is no flexibility as there is a lack of available carers. It is impossible to set things up quickly.

For those of us left behind, along with our grief, we're left questioning whether we did enough. Could we have worked around the system better, could we have done more to give her the death she wanted?

It also doesn't feel like there's a lot of knowledge out there to help. I think more training is needed, to make sure everyone – social workers, GPs, nurses, voluntary sector agencies – knows what Continuing Healthcare can be used for, and how it can work.

Naomi had fallen out with her GP as they had missed the signs of cancer. She lost a stone in a month, steady weight loss of 2-3 lbs a week. By the time the GP acted it was too late. She had already been in to AMU twice, was put on IV antibiotics and sent home.

It's a really complicated system, and there needs to be more support to navigate through the process."

Case study 2

We are unable to use this as a review regarding retrospective funding is still pending and we have concerns about compromising that review.

The main issues are:

- failure to involve carers within the process, specifically giving short notice of meetings, excluding the main carer from meetings, and refusing to provide information against official guidance
- attitude of the staff completing the reviews throughout, reinforcing the idea of them as 'gatekeepers'
- having to explain rights under the process to staff working within it
- abilities of staff outside the Continuing Healthcare process to support those going through it
- differing opinions between those within and outside the process
- no access to ongoing advice, information and support throughout the complex process

Continuing Healthcare issues reported to Healthwatch York

September 2016

A woman contacted us. Her son had moved back to York from out of area in June 2013. He had autism, epilepsy and learning difficulties and was non-verbal. He had a continuing healthcare package for his support. He moved into supported living run by a national charity. There were lots of discussions and some dispute about his funded hours. Eventually the hours were agreed but the family felt this made no difference to the care he was receiving – they felt it was just about funding.

During 2014/15 his parents noticed a deterioration in his behaviour, and observed that he was getting distressed. His parents felt that there was no access to suitable support in York, so they paid for a behavioural analyst who worked with their son and staff to put a support plan in place.

Their son died in August 2015 following a seizure.

The family believe that health professionals were not involved in any of the review meetings. There was confusion regarding his budget and spending – they were told at one meeting that there had been an overspend of his budget at a previous home. This had to be paid back in instalments, meaning he had less money to spend on activities. However, after his death they received a cheque for over £1,000 with a note that this was his money.

The family had a number of concerns. Those most relevant to this report relate to the sharing of information to allow good financial management and personal choice and control. They questioned who was keeping a check on how the budget was spent, in line with the wishes of the individual? They felt this was particularly important where the budget is for someone who is non-verbal and has limited capacity. They felt there needed to be greater flexibility to adjust to changing needs. They also felt that recognising need is only part of the story – "what is the point in a care plan which recognises needs if they are not able to be met due to funding and staffing issues?" There was a review meeting a few months before his death. However, the family felt that the notes did not bear any relation to what happened. There was also no review of his continuing healthcare budget.

August 2015

A woman whose father has been assessed for Continuing Healthcare contacted Healthwatch York over issues with the language used by the Continuing Healthcare team and the suitability of the place offered. She was very unhappy about the impact both on her father's wellbeing and her wellbeing as a carer. She accepts that her father exhibits challenging behaviour but is concerned over the lack of options.

May 2015

A man, aged 92, was given fast track Continuing Healthcare status by Plymouth CCG in September 2014. His children both live in York, and wanted to move their father to a local home. They were told by two homes that "Continuing Healthcare patients could not be accepted as funding was insufficient". The family were happy to top up funding to

allow their preference to be met but were told this is not allowed. Their father was 'stuck on an acute, busy ward for 6 weeks' until a home in Dorset was found. He died there 5 weeks later. The family are concerned about the responses of care homes in York, and the lack of options available to people.

February 2015

A woman supporting her daughter following a serious accident in May 2014 asked about Personal Health Budgets in October 2014. She is still awaiting the follow up to this request. She believes that delays with Continuing Healthcare assessments are the biggest barrier to people receiving Personal Health Budgets.

January 2015 (Issue regarding joint package of care)

A 46 year old man with acquired brain injury has a care package co-funded by City of York Council and Vale of York CCG. He has been admitted to hospital twice due to deteriorating physical health.
His family feel he is "now stuck on ward 21". The family state that Archways refused a referral for rehabilitative physiotherapy due to his challenging behaviour. His care provider states that they cannot take him back unless his physical health improves. His carer is struggling to get alternative options for rehabilitation. She is worried about him being placed in a nursing home. She feels if this happens he won't get the rehabilitation support he needs, and he's only 46. The Patient Advice and Liaison Service at the hospital have been involved. However, they only arranged a conversation with the Archways manager who explained why treatment has been declined. His family feel that carer involvement has been poor throughout – they have received short notice of meetings about care plans, and limited explanation of the options available to them. The carer states that the social worker is not helping and it "feels like no one wants to help resolve the situation."

July 2014

We were contacted by staff and friends supporting a man with dementia, at a care home with nursing in York. They had tried to get a Continuing Healthcare assessment. The man had continence issues and limited

mobility, but those supporting him struggled to get any information about when he might be assessed.

December 2013

A family contacted us after a conversation with the Care Quality Commission about their experiences. They have been looking for a nursing home for their father to move to following a stay in an intermediate care facility in York. They feel that their experience has been ‘awful’, and that they are being pushed hard to find something quickly. They believe that their father has only had a social care assessment, not a continuing care assessment. The family were not made aware that a formal report had been completed. They have had to push for information all the time, and there is no communication or involvement in decisions as they are being made. Their father has capacity, but a number of physical health needs. They believe that the nurse in the discharge team who completed the assessment did not see their father in completing the assessment.

The family believe that the attitude has been "well, he can pay" rather than assessing his needs. They were looking into a nursing home in York, but were informed about a safeguarding issue within the home. They informed discharge staff of this to explain why they were not pursuing a place in that home. When they arrived to visit their father shortly afterwards they found a representative of the same nursing home speaking to him.

The family felt staff at the intermediate care unit had called in the nursing home representative as they "want to get rid of him". Their father went into hospital in August, and on to intermediate care in October. But they feel that no one communicated with the family through the process. Now, they feel that because the unit wants him out, it is demanding instant decisions about long term plans involving compromises which the family are not willing to make.

Other issues related to funding of care – where it is not clear if Continuing Healthcare was involved

July 2016

A family reported that their father, who has dementia, was in hospital from early April to mid-June in 2016. The hospital informed the family they needed the bed, so the family began looking for a suitable care home. There was limited availability. The family were told that a particular home would not take him as he wanders in the night. That home sent someone to assess him, and he moved into the home in the middle of June 2016. He was in the home for a month before the family were called into the office. The manager said their father was getting up in the night, walking around naked. They informed the family the home wasn't set up to cope with this behaviour so the family needed to pay £214 per night for 1-2-1 care. They state that the care home said the hospital had lied to them as they hadn't known he would need care overnight. He did have a pressure sensor on the mattress which raised an alert if he got out of bed. The family initially agreed. They subsequently realised this additional charge doubled the cost for them and started to question this. They contacted the home to explain they did not want to pay the charge. The manager said that the home would have to do an emergency eviction. The family live 150 miles away. They feel they were forced into accepting a place at an unsuitable home and then forced into paying for additional care. Their father has now moved to a different home, and is much happier.

May 2016

A man with lung cancer and significant care needs was admitted to York Hospital. His daughter lives in York and was invited to a discharge meeting at the hospital, at which her father was not present. She wanted to get him home and was willing to be his carer as her work was very flexible so she could do so. But he needed oxygen, a hospital bed, plus some care, roughly a day a week to enable her to attend work commitments. At the discharge meeting, she was told that they could have either 4 daily visits at home, or he could go into a care home. She asked about Personal Health Budgets as a way of meeting his

healthcare needs. She was informed that York doesn't do Personal Health Budgets for people who are fast tracked. She was also told to put it in writing to them because they are "sourcing new care." A further comment was "If you apply for a Personal Health Budget he will die before we respond. He only has 6 weeks to live." At this point she had believed her father had 2-3 months to live and it was left to her to inform her father he had 6 weeks to live.

The man went home and had the 4 daily visits from a home care agency. His daughter reported that the home care agency were great. He also received support from hospice at home.

The daughter had concerns about the discharge – she was given a big bag of medicines but did not feel she received adequate information about what these drugs were for. She also felt that overall there was a lack of communication, co-ordination and clarity of responsibility between the hospital, hospice team and home care agency. She felt that the process was as far as it could be from being person centred.

She believes there is a need to improve staff awareness of Continuing Healthcare. She felt that both cancer care staff and Macmillan nurses should have been aware of the Continuing Healthcare process, and proactively informing patients and families about it. She stated that none of the staff she spoke to at the cancer care centre had heard of it.

She also recommends that there should be an end of life care helpline for people locally.

April 2016

A man with learning difficulties and communication challenges was diagnosed with cancer in February 2015, but refused an MRI scan. The family have been informed his condition is terminal. He went into hospital and was discharged in June 2015. He accessed the reablement team, which was originally meant to be for 6 weeks, but this continued until December 2015. The family received a call from City of York Council about completing an assessment which the family believed was for Continuing Care. They came to complete the assessment in January 2016. This was witnessed by a Macmillan nurse. A financial assessment

was completed and it was determined that the man had to pay a certain amount towards his care. The family assumed this was from the date of assessment, but the council has now said it was from the date of discharge from hospital. The family say they are being asked for thousands of pounds. The man is on benefits and does not own his home. He and the family are all very unhappy, and feel they were never given any information about costs or options. There was no contact from June through to the end of November. The family are now trying to make alternative arrangements but they do not live locally. They have queried some of the charges, and state that the council has said they can't amend the invoice but will reimburse for any care not provided at the end of the year.

March 2016
A person contacted us seeking advice on addressing challenges with securing Continuing Healthcare funding for an individual. Healthwatch York signposted the caller to York Advocacy.

February 2016
A person on Continuing Healthcare fast track with nursing care needs is adamant they do not want to go into a nursing home but they need considerable care. They wanted to look at having a live in companion to help under a personal budget but were told this is not possible. They feel they are being left with no choice, and that their last weeks of life will not be lived in the way they want them to be.

January 2016
A person made contact with Healthwatch York to seek advice on appealing a decision not to provide Continuing Healthcare funding. They were signposted to York Advocacy for support.

November 2015
A woman's relative is currently living in a residential care home but needs to move to a care home with nursing. She is not in a position to top up fees and her social worker has told her that she can move to one of three nursing homes.

The caller was aware of some work to address concerns at one of the homes, and wanted to know what would happen if placements at all homes were suspended. The council confirmed that this would be looked at on a case-by-case basis.

She is also currently investigating whether or not her relative qualifies for Continuing Healthcare and wanted to know whether there would be additional choice if they were eligible. She was encouraged to make contacting with the Continuing Healthcare team to discuss this.

September 2015

A family contacted us regarding the appropriateness of supported housing where no staff members are able to communicate in British Sign Language (BSL) with the individual. The family member is now exhibiting signs of depression due to isolation and lack of external stimulation. The current housing was meant to be temporary but the family member has now been there for 2 years. The family has proposed alternatives, but all have been turned down. The family has never been offered the chance to explore personal budgets or personal health budgets.

Further information

At the end of the process of writing this report we were made aware of Beacon Continuing Healthcare.[xxii] NHS England have a contract with Beacon to provide an NHS Continuing Healthcare information and advice service.

They say:

“If you have a question, would like us to discuss your assessment or need to talk to someone independent about your situation, please call us on 0345 548 0300 or send us a ‘Talk to us’ request to schedule a free consultation with a trained NHS continuing healthcare adviser.

We are able to provide you with up to 90 minutes of free written or verbal advice in addition to our free literature. We will also signpost you to other trusted not-for-profit organisations where we feel they may be able to provide you with expert advice on matters related to your situation. Please note that our free advice service is kept entirely separate from our casework services – we will not try to sell you anything and will only put you through to the casework team if you ask us to.

This free information and advice service is officially supported by a number of the UK’s leading charities including Age UK, Parkinson’s UK, Spinal Injuries Association and First Stop EAC.”

We hope the inclusion of this information helps to raise awareness. This service was not mentioned by any of the people who contacted us during the writing of this report.

Conclusion

Continuing Healthcare conversations and assessments take place at a highly stressful time in peoples' lives. Patients and families going through the process struggle when they don't have access to support.

Patients and their families don't have enough information about NHS Continuing Healthcare at the time they need it.

Some health and social care staff lack awareness about Continuing Healthcare and Personal Health Budgets and so they are unable to provide support to patients and their families.

The Continuing Healthcare assessment process is supposed to be person centred, but from the experiences we have heard about, it doesn't always seem to be.

There are also challenges with accessing the care needed. The levels of funding and care availability in our area mean the options are often severely limited. More work is needed to encourage care homes and home care agencies to help address the lack of choice.

It is even more important to get this right when patients have received a terminal diagnosis.

Recommendations

Recommendation	Recommended to
Look at ways to improve staff training and awareness around Continuing Healthcare, eligibility and assessment.	NHS Vale of York Clinical Commissioning Group, City of York Council, Care Homes, GP practices, York Teaching Hospital NHS Foundation Trust
Look at ways to improve access to information about Continuing Healthcare for individuals, families and carers.	City of York Council, Care Homes, GP practices, York Teaching Hospital NHS Foundation Trust, working with York Carers Centre
Consider options to increase proactive support and advocacy services to those going through the Continuing Healthcare process. This may include, but is not limited to, increasing awareness of the NHS England commissioned BEACON information and advice service.	NHS Vale of York Clinical Commissioning Group
Increase access to Personal Health Budgets and consider ways to make this possible for fast tracked patients.	NHS Vale of York Clinical Commissioning Group
Look at ways of increasing flexibility for families facing end of life. This should include consideration of issues like top-up fees and where these might be permitted.	NHS England
Work together with existing providers of care services to identify ways of increasing choice and access and encourage a wider range of placement options.	City of York Council / NHS Vale of York Clinical Commissioning Group
Work together with existing providers of care services to encourage more feedback, helping the system better understand the experiences of people going through the NHS Continuing Care process, including making routes outside the NHS and social care system clear to patients and families (for example York Carers Centre, York Advocacy, Older Citizens Advocacy York, Age UK York, Healthwatch	NHS Vale of York Clinical Commissioning Group

York, single condition groups such as York MS Society, York Parkinson's Support Group, etc)	

Acknowledgements

We would like to thank everyone who took the time to share their experiences with us.

We let the Partnership Commissioning Unit know about our work, and encouraged them to contact those individuals they were working with. We always want to hear from as many people as possible, to show the range of experiences people have. We wish to champion the good alongside the areas where improvement is needed. Unfortunately, despite this, we were only able to reach a small number of people through our own publicity and networks, most of whom had experienced problems either with the process or the care provided. This is perhaps to be expected, given the low number of people who receive Continuing Healthcare, and the complex health needs people who do are living with.

However, every example we share is somebody's story. Every experience could be our experience. Our role is to give voice to those who want to be heard. We could not do this without you. We believe that together we can all make York better. Thank you for trusting us with your words.

References

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[xii] Ibid
[xiii] http://www.nhs.uk/NHSEngland/complaints-and-feedback/Pages/nhs-complaints.aspx
[xiv] http://content.digital.nhs.uk/catalogue/PUB20890
[xv] See for example the papers of the meeting on 5 January 2017 http://www.valeofyorkccg.nhs.uk/governing-body-meetings/governing-body-meeting-5-january-2017
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[xxi] http://www.yorkpress.co.uk/news/13524146.Investigation__being_considered__over_awarding_of_mental_health_contract/
[xxii] http://www.beaconchc.co.uk/national-nhs-continuing-healthcare-information-advice-service/

Contact us:

Post:	Freepost RTEG-BLES-RRYJ Healthwatch York 15 Priory Street York YO1 6ET
Phone:	01904 621133
Mobile:	07779 597361 – use this if you would like to leave us a text or voicemail message
E mail:	healthwatch@yorkcvs.org.uk
Twitter:	@healthwatchyork
Facebook:	Like us on Facebook
Web:	www.healthwatchyork.co.uk

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